



## Advancing the human and civil rights of people with disabilities

SELF-ADVOCACY ASSISTANCE ★ LEGAL SERVICES ★ DISABILITY RIGHTS EDUCATION ★ PUBLIC POLICY ADVOCACY ★ ABUSE INVESTIGATIONS

October 28, 2013

Krysta Heaney, MPH  
Office of Health Information Technology  
100 W. Randolph Street, Suite 2-201  
Chicago, IL 60601

**Re: Comments of Equip for Equality Regarding the Proposed Notices, Forms and Policies to Implement the Amendments to the Mental Health and Developmental Disabilities Confidentiality Act (P.A. 98-0378)**

Dear Ms. Heaney:

Equip for Equality (EFE) is an independent, not-for-profit organization designated by the Governor in 1985 to implement the federally mandated Protection and Advocacy (P&A) system for people with disabilities in Illinois. EFE's mission is to advance the human and civil rights of people with disabilities and is accomplished through self-advocacy technical assistance and training, legal services, public policy initiatives, and investigation of abuse and neglect. EFE appreciates the opportunity to provide comments on the proposed notices, forms and policies (Attachments A-G) for implementing the recent changes to the *Mental Health and Developmental Disabilities Confidentiality Act* (MHDDCA) contained in P.A. 98-0378.

**The Notice to Patients and other documents are insufficiently clear regarding the impact of P.A. 98-0378 on the confidentiality of mental health records**

Historically, people with mental illness have been subjected to discriminatory attitudes and treatment, which has resulted in significant stigma and shame. To encourage and support individuals with mental illness to seek and obtain treatment voluntarily, the MHDDCA was enacted to provide strict rights of confidentiality regarding the use and disclosure of mental health records. Until recently, an individual's mental health records could generally not be disclosed unless the individual signed a time-limited consent authorizing their disclosure to a specified party for a specified purpose.

The amendments to the MHDDCA embodied in P.A. 98-0378 represent a fundamental

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alteration of the rights of confidentiality that people with mental illness have been afforded for decades. The new law authorizes mental health records to become part of the Illinois Health Information Exchange (ILHIE) network, and allows that information to be used, disclosed and re-disclosed to third parties without the individual's consent—*unless* the individual expressly declines or opts-out of further disclosure. To ensure that patients are able to make meaningful decisions about whether to participate in ILHIE and EHR Connect, it is imperative that the information provided to them regarding their rights and options clearly and explicitly sets forth the changes to the MHDDCA.

The proposed Notice to Patients (Attachment A) attempts to convey this information, but does so in a way that does not make explicit that mental health records will be shared through the ILHIE and EHR Connect *unless* the patient opts-out. For this purpose, it is not enough to say that previously it was necessary to give consent to share mental health records—or that special consent is still needed for psychotherapy notes. To ensure that patients understand the practical effect of P.A. 98-0378, the Notice should clearly state that under the new law consent is not required to share mental health records. It should also explicitly state that mental health records will be shared through the ILHIE and EHR Connect unless the patient opts-out. Moreover, it should be made clear that in order to keep mental health records from being shared the patient must complete the Opt-Out Form.

The significance of P.A. 98-0378 and its impact on the long-standing rights of confidentiality of individuals with mental illness was repeatedly raised by EFE and others during the workgroup meetings. While this provision of the Notice has undergone several iterations in the process, it still does not clearly set forth what the statute does or requires. The possibility that some individuals, upon being given notice of the changes imposed by P.A. 98-0378, may choose not to participate in the ILHIE and EHR Connect does not justify providing a Notice that is less than complete or forthcoming. To be effective, the Notice must be crystal clear regarding what the change in the law is and how it will impact the confidentiality of mental health records. Absent that clarity, the meaningful disclosure requirement of the statute will not be met.

#### **Rights and other patient information should be set forth in simpler language**

Implementation of the ILHIE and EHR Connect represents a significant shift in the way healthcare records are managed, used, and stored. It is therefore critical that the information provided to patients regarding their rights and options is stated clearly and simply and that easily understood words, terms and explanations are used/ provided.

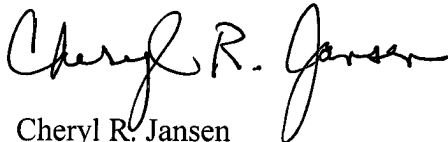
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Throughout the workgroup meetings, EFE and others stressed the importance of making these documents user friendly, meaning that they be written at a fifth grade reading level. In response, workgroup members were assured that these documents would undergo review and revision for that purpose. However, EFE remains concerned that these documents do not satisfy that requirement and, as a result, will not allow patients to make truly informed decisions about their participation in the ILHIE and EHR Connect.

Equip for Equality wishes to thank the ILHIE Authority and the Office of Health Information Technology for the opportunity to participate in the Meaningful Disclosure at the Point of Care Workgroup and also to submit comments regarding the documents (Attachments A-G) to be considered by the Data Security and Privacy Committee.

Sincerely,

A handwritten signature in black ink, reading "Cheryl R. Jansen". The signature is fluid and cursive, with the first name "Cheryl" and last name "Jansen" clearly legible, and "R." as a middle initial.

Cheryl R. Jansen  
Legislative Director